ILEP

Guidelines to reduce stigma

Guide 2

How to assess health-related stigma

2011
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Introduction

This Guide is part of a series of four Guides to reduce stigma. The Guides are for all managers, health and social workers and service staff who have to deal with stigma in leprosy and other health conditions. These Guides provide evidence-based and best-practice information from different disciplines, and recommendations for field workers on how to reduce stigma against and among affected persons and in the community.

This second Guide describes when and how to assess stigma using qualitative and quantitative methods and instruments. It also explains how to use the instruments. The first Guide provides basic information on stigma, its causes, manifestations, and effects. The third Guide provides recommendations on how to develop an approach for reducing stigma. Through the use of a roadmap, several steps are discussed for reducing stigma related to a particular health condition. The fourth Guide explains the use of counselling at a basic level in dealing with stigma. It provides an explanation of different techniques and approaches for counselling persons affected by stigma.

For supporting documents: www.infolep.org/stigma-guides

Contents

Why is stigma assessment important?

Assessing stigma is important so you can:

- Analyse the stigma situation in your area, the service you work in, or among patients or people you work with. Is there stigma? What kind of stigma? How widespread or severe is it? What is the impact of stigma?

- Monitor how levels of stigma change over time. Is there a difference in the situation now, compared to some time ago? Has stigma decreased or increased?

- Assess the effect of interventions to reduce stigma. Have the levels of stigma come down following the interventions? Who has most benefited from the interventions?

More information is provided in the annexes or available at:
www.infolep.org/stigma-guides

1. What is the purpose of assessment?

The purpose of assessing stigma may differ in different situations. Before you are able to choose an adequate method and instrument, you should be able to answer the following questions:

a. Why do I want to assess stigma?

b. What is the target group? (Guide 1 'What is health-related stigma' explains that everyone can stigmatise so you need to decide which groups you wish to focus on: affected people, community, health professionals, and / or other?)

c. Which health condition do you want to address?

d. What type / aspect of stigma do you want to assess?

e. What would you like to do with the results?

Guide 1 'What is health-related stigma' assists in defining the purpose of and target group for stigma assessment. The current Guide helps you to choose the most appropriate tool to do so. Also, recommendations are given for applying your results.

2. What approach would best fit your purpose and context?

When considering the approach of your assessment, you should take the following two questions into account;

1. **What method would best fit my purpose?**
   Section 2.2 and 2.3 described qualitative and quantitative methods. There are many different methods for assessing stigma. This Guide focuses mainly on quantitative measures, but also provides some information for considering a qualitative approach.

2. **Which context-specific conditions do I need to take into account?**
   Consider what might be specific to your situation or population. Think of potential barriers and how to anticipate these. For instance: education, available time, cultural and language barriers, appropriateness of measuring in the target population, availability of questionnaires or other equipment (for example pen, paper, a voice recorder and tools for data analysis).

What is important when you assess stigma?

The reasons for stigmatisation can be different in each affected person or community, due to local culture, norms, beliefs and values, government policies, stakeholders, etc. Therefore, these Guidelines may need to be adapted to your specific setting taking these factors into account. A few should be considered in every context.

a. When choosing an instrument it is important to consider the **burden on the respondents**. What is the educational level of the respondents? How much time is the measurement likely to take? Is the level of difficulty of the questions suitable for these respondents? Certain questions are likely to have a big emotional impact on the respondents – is someone available to whom a distressed respondent can be referred for help?

b. Ensure adequate **privacy** for the assessment interview. The respondent should feel comfortable to give honest feedback. Therefore, try to make sure that a quiet place is available to conduct the interview.

c. Before the interview, informed **consent** should be asked of each interviewee in a language and form that is understandable to the person concerned,.

d. Questionnaires and other tools should always be translated into the **local language** so that the interviewer does not have to translate the questions during the interview.

e. The questionnaires should first be **trialled** on a few persons, before using them with a larger number of people (see Annex 1).

f. The **training of interviewers** is essential to get good quality information. Interviewers should have the necessary knowledge about stigma and the importance of assessing it, besides the right attitude and skills to administer the questionnaire / interview (see Annex 1 for elaboration on these points).

What method do you want to use to assess stigma?

To assess the nature of stigma or the extent or severity, you can use qualitative or quantitative methods, or preferably a combination of both (see Annex 2 and 3 for elaboration of each qualitative and quantitative method).

- Thematic interviews, focus group discussions and observations are examples of qualitative approaches to assess stigma. They may be used on their own or in combination. You can use such methods when you want to get answers to more in-depth questions like **why** stigma exists, **how** it manifests or **when** it occurs. In general, these methods are explorative and give you in-depth information. Often the number of respondents is smaller than when using quantitative methods, because qualitative methods are more time consuming.

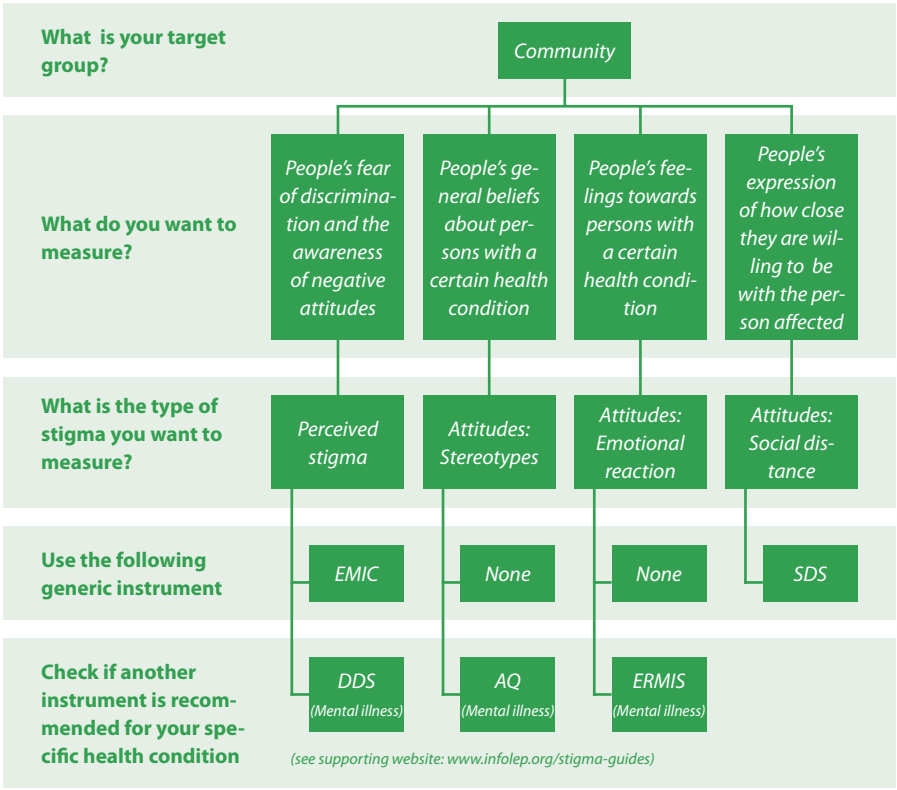
- Quantitative methods provide you with information on what **type of stigma** exists, **how widespread** the stigma is and **how severe** it is. This information is collected in a structured way so results can be compared between groups of people, points in time or different settings. Often questionnaires can be structured in order to generate a score to make comparison easier.

- It is recommended that you combine both approaches. This will give you the most in-depth and accurate picture. The results can complement each other, but also be used to validate each other.

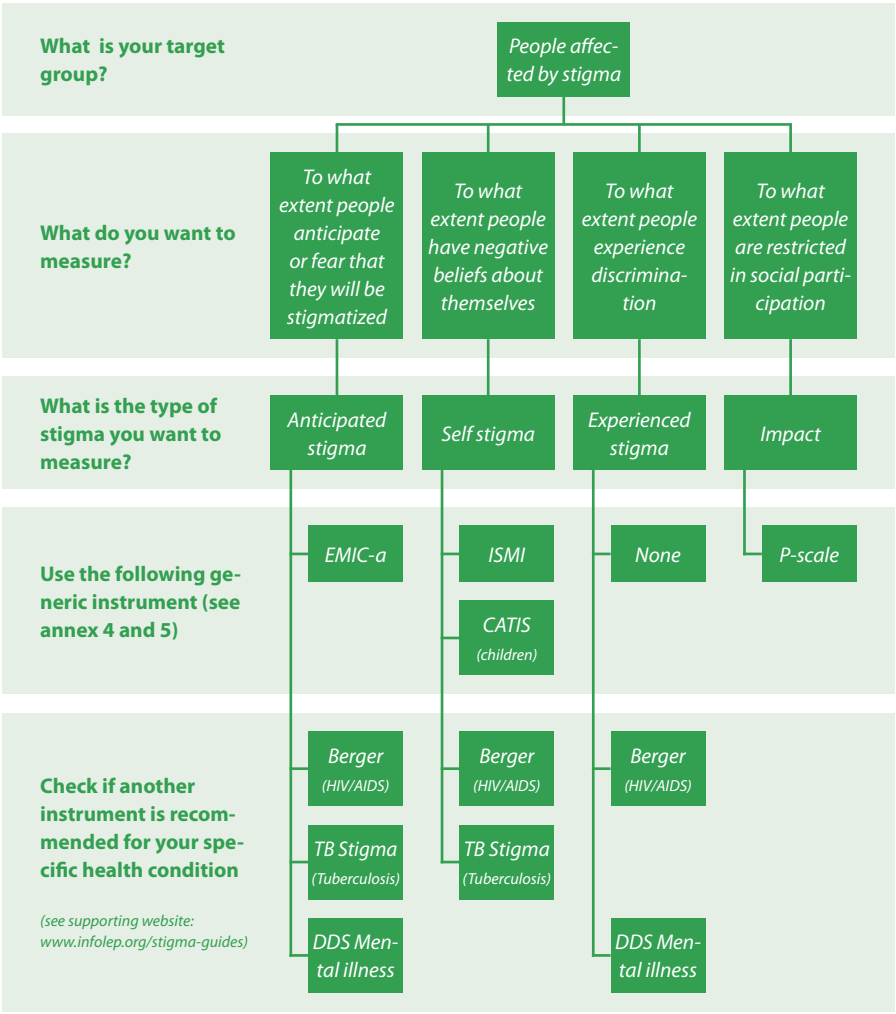
3. Which instrument should you use?

Use the flowcharts on the following pages to see which instrument is recommended for your purpose.

If you want to get a more complete picture of the problem of stigma in your area, you will need to assess several aspects of stigma. This will require using several instruments. For example, measures of anticipated stigma, self-stigma, and impact of stigma are often combined.



Instruments for measuring stigma in the community



Instruments for measuring stigma with affected persons

4. Is this instrument already available for your target group and language?

Look up the recommended instruments in *Annex 5* and carefully consider whether this instrument is appropriate for your purpose of assessing stigma. Try to answer the following questions:

1. Was the tool originally designed for my target group or has it been validated for this group?

2. Is the questionnaire available in the appropriate language?

If one or both of these questions are answered with 'no', you might still choose to use the instrument, but it will require more preparatory work. However, you should always carefully check the formulation of the items and judge whether they are appropriate to use in your target group. In case you want to use this for scientific purposes, you need to do a validation study first (see Annex 2).

5. How do you conduct the stigma assessment?

Please see *Annex* 1 for more details on the following topics:

a. Translation and back translation (validation)

b. Field testing (validation)

c. Selection of people

d. Training

e. Respondent (section: Building a relationship with the respondent)

f. Ethical considerations

Consider beforehand:
It is important to consider the following before you start with the stigma assessment. This may save you time during the assessment and analysis.

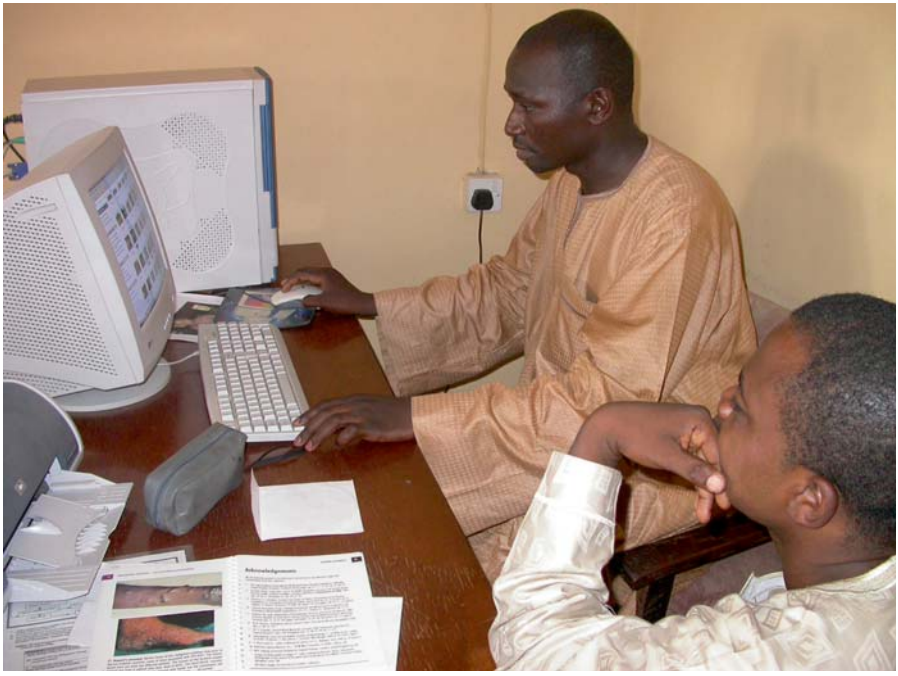
- How will you interpret the results?

If you use one of the recommended measures, check the 'tips' and 'pay attention!' sections. This describes if and how you could calculate a sum score.

- The tools you need for recording and analysis

For recording your findings you may need to print the forms and you need pencils or pens to fill in the forms. Also, you may need to use a computer to make a database and to calculate the stigma scores. If you conduct qualitative methods, in some cases is may be benefical to record the interview with a recorder.
If you conduct your stigma measure among a larger group, e.g. more than 20 persons, it is recommended to create a digital database. You can enter the stig-

ma score(s) and other relevant information on your participants. It will also help you analyse the results. Databases for the various stigma measures may already be available. Please contact Infolep to find out (www.infolep.org).



6. How to interpret and report your findings

This last step concerns the dissemination of your findings and evaluation of the process. The following questions should be asked:

a. What is the best way to report my findings?

b. What will be the end product (e.g. an internal report, a report to the government or a donor agency, a policy document, or also a scientific article)?

c. How can we best use the results?

d. Who should be informed about the findings? Consider who your stakeholders are and for whom your findings may be useful.

e. What went well, what went wrong? Evaluate whether things should be improved or changed for future assessment of stigma.

If you have found that people are being stigmatised, you may want to consider implementing interventions. Guidelines for developing an approach to reduce stigma are described in Guide 3: 'A roadmap to stigma reduction'. Specific guidelines on counseling in stigma are elaborated in Guide 4 'How to do counseling in health-related stigma'.

Further reading

Please see the website www.infolep.org/stigma-guides for:

- supporting documents
- stigma assessment instruments (including translations)
- links to websites
- further background reading
- persons you can put questions to
- practical tools and guides

Annex 1: Assessing stigma in the field quantitatively: a practical elaboration of the Guidelines

Only generic instruments have been included in this Guide. Others that are recommended for use with specific health conditions are available on the website www.infolep.org/stigma-guides.

Translation and back translation

Questionnaires and scales should always be used in the local language of the interviewees. It is bad practice for interviewers to translate the questions during the actual interview. If the selected instrument is not yet available in the language(s) of your target population, you need to translate the questionnaire. To avoid mistakes, it is recommended you first translate the questionnaire and then translate it back to the original language, often English. In this way you can see whether the meaning of the questions has remained the same.

The translation into the local language of the target population should be done by someone whose mother tongue is the same as that of the target population, who is also fully conversant with the original language of the questionnaire and who has an adequate technical understanding of the subject of the questionnaire.

The back translation should be done by someone who is fluent in both languages and who is NOT a technical expert in the subject of the questionnaire. Small differences are likely to occur, but you only need to reconsider the translation of a specific question when the meaning has changed from the original during the translation process.

Field testing (validation)

Before you use the questionnaire with many people, you should first test the questionnaire and the interviewing procedures. Select a small number of respondents with whom to administer the questionnaires for the first time. It is important to get to know the experience of both the interviewer and the respondent. During this testing phase, you need to keep the following in mind.

- Questions may be interpreted differently in other cultures or languages.
- You need to know whether the respondents of your target population are able to understand the questions correctly. The questions may need simplifying or rephrasing.
- The interviewer needs to know which questions may be sensitive to ask, and how to react when a respondent hesitates or refuses to answer.
- To plan the number of interviews to be conducted in a day, it is useful to time the duration of the interviews during the testing phase.

Field testing or validation is a procedure to make sure that the questions in the questionnaire work well in your local context. If certain questions are problematic during the testing phase, you need to adapt the wording, but without changing the meaning behind the question. Also, adding appropriate examples can be helpful. If a question is completely inappropriate in your cultural context, you can delete the question. You can change a question to a more locally appropriate question by rephrasing or simplification. For example, you can choose to use local language or events relevant to the cultural context.

Selection of people to interview

When conducting a questionnaire survey, the number of respondents you need depends on the purpose of your survey. If you only want to estimate the level of stigma, e.g. the percentage of people with negative attitudes (i.e. perceived stigma), you should aim for a sample of about 100 respondents from your target population for an accurate estimate. To get a sample that is representative of your target population, you need to make an appropriate selection. This selection needs to resemble your target population as a whole. So if your target population is half male and half female, and three quarters live in a rural area, you need to try to get the same balance in your selection.

One way to achieve this balance, for example in a household survey, is to select the households in such a way that every household has an equal chance to be

included in your selection. If you want to include 100 households in a certain village that consists of 500 households, you randomly choose the first household, e.g. by throwing a dice, and then select every fifth household based on lists of the municipality or another developmental organisation (NGO). If no lists are available, you can also select every fifth house in subsequent streets until you have interviewed a sufficient number of people.

Training

You and your interviewers should be familiar with the questionnaire as a whole before using it to interview respondents. One way to get familiar with the questionnaire is to interview each other using role play. Ask yourself whether you understand the meaning behind the questions and whether the translation and answer options are easy to understand. If they make sense to you, you are more likely to be able to explain the questions to your respondents. Next, get the interviewers to test the questionnaire with a small number of people. Make sure that they have information about the purpose and the planning of the survey. It is essential to train your assistants to interview the respondents in an open and non-judgemental way.

Building a relationship with the respondent

To get good quality answers, interviewers need to build a relationship of trust with the respondent. They should introduce themselves properly and tell the respondent how the interview will take place, how long it will take and why their help is important. Before starting the interview, consider the following:

- Does the respondent have enough time to answer all the questions? If not, ask for an appointment on another day
- Find a place where the respondent feels comfortable and at ease. Preferably, this is a relatively quiet and anonymous location.
- Tell the respondent that there are no right or wrong answers. It is important to know what the respondent thinks.

- In some countries or areas, respondents prefer the interviewer to be of the same gender. Make sure that there are both male and female interviewers.
- Give respondents time to answer the questions and do not rush them.
- Tell the respondent that they can end the interview at any time, and they are not obliged to answer questions if they do not feel comfortable answering them.
- Explain what will happen with the data after the interview, specifically how confidentiality is ensured.
- Explain beforehand whether or not an incentive will be given, so that respondents know what to expect.

Ethical considerations

Before interviewing a respondent, it is essential to obtain their 'informed consent'. Informed consent means that the interviewer explains the purpose of the interview, and the risks and benefits of participation before asking the respondent to participate. If your stigma investigation is not being done for research purposes, verbal consent will be sufficient.

Annex 2: Using interviews to assess stigma in the field

Qualitative methods, such as interviews, can be used among people who are affected by stigma due to their health condition. But also among the (general) population who may stigmatise the people who have a health condition.
In practice, doing an interview is a matter of sensitivity, well-formulated questions and good listening. Before using a qualitative method in practice, consider the following points:

- Make a topic guide on the themes you would like to address

- Formulate specific questions for each of these themes, and check if these are;
  - open questions (i.e. that cannot simply be answered with a yes / no)
  - questions without a double meaning or interpretation
  - questions that do not already lead your respondent to a particular answer or direction (wording)

- Ensure as much as possible that the person feels at ease as this encourages them to give honest answers. For instance, a private and quiet room / place (this builds rapport).

- Probe to get in-depth information. By using questions such as: Why? How come? Had you experienced that before? How did this feel to you?

- Try to be objective; do not judge.

- Preferably use a trained interviewer or ask someone else to give you feedback.

To give you guidance in applying a qualitative approach, examples of topics are provided to explore each type of stigma through addressing different topics.

Exploring stigma among persons affected by stigma

- Self-stigma:

You can ask questions about dealing with the disease, whether having the disease has changed the participant's self-esteem or dignity. Feelings of fear, shame and guilt can be explored. A participant may, for example, feel to blame for their own health condition, thinking that they must have been leading a bad life and that they are being punished for it now. Are there changes in their social life, work or educational practices, and what inspired those changes? Participants may, for example, describe choosing to avoid hugging and kissing family members out of their fear of contagion.

- Perceived or anticipated stigma:

People with a stigmatised health condition can fear that other people will react to them in a certain negative way. To avoid this negative reaction, people with a stigmatised health condition may change their own behaviour. For diseases that are concealable, such as HIV / AIDS, this can manifest itself by choosing not to tell others about the disease (no self-disclosure). For diseases with visible manifestations, this can result in withdrawing from social interactions, such as avoiding places of worship and hiding in their own home. You can therefore ask about the changes in their life after being diagnosed with their disease and whether these changes had to do with fear of certain negative reactions.

- Experienced stigma:

You can ask about the experience of negative reactions or actions by other people because of their health condition.

Exploring stigma among those who stigmatise

You can ask the people that do not have the health condition under investigation to what degree they feel, think or act negatively towards people with the disease or towards the disease itself. But you can also ask whether these people perceive or have indeed observed acts of stigmatisation in their environment.

- Attitudes and beliefs

To explore this type of stigma, you can ask how the participant views the health

condition itself, what ideas come to mind when hearing about the disease, what feelings does the participant have when thinking about the disease. Furthermore, you can ask how the participant views people with the health condition under investigation. Do they think leprosy affected people are in some way different? How contagious are they? In the opinion of the respondent, are they in some way to blame for their disease? Are they responsible for getting the disease?

- Perceived stigma

You can ask the participant how they perceive people in their environment think and feel about the disease and people having the disease.

- Enacted stigma

You can ask the participant how people with the condition or disease are being treated in their environment. How do people in the community react to people with the disease? Are they treated differently, and how or why?

Annex 3: What are the advantages and disadvantages of the different approaches to assess stigma?

The table below summarises the methods and techniques used and lists the advantages and disadvantages of each method.

Table 1: Overview of qualitative and quantitative methods used for stigma assessment with their advantages and disadvantages

Table 1			
Methods to assess stigma	**Short description**	**Advantage**	**Disadvantage**
Qualitative methods			
Interviews	An interview is basically a conversation between you and someone else in which you ask questions to get information about a certain topic	Can be used in settings where there are many people who cannot read and write You can always clarify your questions, explain in more depth what you mean, or what you want to know	The presence of the interviewer and way of questioning can influence what the respondents say or how they say it Reports of events may be less complete than information you would get through observation
Focus group discussion	A group of persons brought together to discuss specific issues under guidance of facilitator. The group is usually between 6-12 persons with more or less the same characteristics (for example: • persons with leprosy, or another health condition	You can explore further issues that came up in individual interviews You can use this method to learn relatively quickly about different perspectives on issues It becomes possible to discuss and evaluate issues together	People may not want to talk in each other's presence about certain sensitive topics If you want to know about what people really do, thus actual behaviour, a focus group discussion is not suitable. With a focus group you will have group norms, rather than individual ideas and practices

Table 1

Methods to assess stigma	Short description	Advantage	Disadvantage
Focus group discussion	• only women who have children • only teenagers In a focus group, participants can express their feelings, opinions, beliefs, experiences etc. They have also the chance to react to each other		
Observation	Observation is a way of collecting information about behaviour and characteristics of people, objects or certain phenomena by watching and recording one's observations systematically	Observation is complementary to interviewing, because it allows you to record different things, such as: information about facts that people did not (want to) tell or describe in the interviews; whether the responses during interviews are reliable	Your presence can influence the way people usually behave. They may or may not do certain things because of your presence there This method only provides you with information you can actually observe, and not the reasons for people acting, feeling or thinking as they do The way you interpret the information may differ from how other persons experience the situation
Vignette	A short description or example of a person, event, or behaviour to which respondents are asked to react, give their opinion A vignette is complementary to an interview or questionnaire (See description above)	By sketching a situation, the respondents are better able to imagine how they would act A vignette is less personal and therefore an excellent way of collecting information on sensitive topics	A vignette is still a hypothetical situation; there is no guarantee that a respondent will react to a real-life situation in the same way as to a vignette.

Table 1			
Methods to assess stigma	**Short description**	**Advantage**	**Disadvantage**
Vignette		This method is often used in combination with a questionnaire (see description below)	You can use this only in combination with other methods, especially within a questionnaire (see description below)
Questionnaire	It is an instrument consisting of a fixed series of questions. Together, these questions provide information on certain topics, such as a particular type of stigma	The set of questions may have been previously used and developed according to a certain theory, found to be practical in use, and tested as to whether it provides information about what you want to know A questionnaire interview requires less skill from the interviewer than qualitative measures (e.g. in conducting and assessing the interview)	Questionnaires give limited information and only on the questions included in the instrument Questions might be interpreted differently across other cultures and countries. Also, sometimes people are not used to answering the type of questions used in questionnaires. This may influence the validity of the responses
Scale (questionnaire)	A questionnaire intended for measurement. It is an instrument consisting of a fixed series of questions that belong together. Responses are scored on a numerical scale (e.g. 0-4). The purpose is to quantify the information from respondents on a specific issue, such as stigma	Scales give a numerical score. The score says something about the presence or absence of stigma, as well as the severity Scale interviews can be conducted with much larger numbers of respondents than in-depth interviews, so that you can study a representative sample of the population The scores can help in monitoring changes over time	Scales give limited information, only on the questions included in the instrument Scales do not tell you *why* a person gave a particular answer In many developing countries, people are not used to answering the type of questions used in scales. This may influence the validity of the responses

Annex 4: Brief description of each recommended instrument for generic use

Anticipated stigma

Explanatory Model Interview Catalogue (EMIC) stigma scale for affected people	
From the perspective of:	Stigmatised
Measures:	Perceived (and self) stigma
Health condition:	Leprosy, HIV / AIDS, disability, generic
Languages:	Available in multiple languages, including: English, Bengali, Nepali, Tamil
Number of questions:	15, 17
Answer options (score):	4 options: Yes (3), possibly (2), uncertain (1), no (0)
Method of administration:	Interview-based
Outcome:	Item sum score. The higher the score, the higher the level of perceived stigma
Tips:	The scores on the single questions should be added up to get a sum score. Before calculation of the sum score, question 2 should be recoded to get the correct results question (3→0, 2→1, 1→2, 0→3)
Pay attention!	One reverse coded item (item 2)
Generic application:	Yes, insert the specific health condition into the questions

Self-stigma

Internalized Stigma of Mental Illness (ISMI) scale	
From the perspective of:	Stigmatised
Measures:	Self-stigma (or internalised stigma)
Health condition:	Mental illness, leprosy, HIV / AIDS, disability, generic
Languages:	Available in multiple languages, including: English, Greek, Tamil, Bengali
Number of questions:	29
Answer options (score):	4 options: Strongly disagree (1), disagree (2), agree (3), strongly agree (4)
Method of administration:	Interview-based
Outcome:	Mean of all items. The higher the mean score, the higher the level of self-stigma
Tips:	The ISMI consists of five components namely alienation, stereotype endorsement, perceived discrimination and social withdrawal and stigma resistance. The five questions in the stigma resistance component are reverse coded. For the calculation, five items should be recoded to get the correct results. Subsequently, the total score can be calculated by dividing the sum of all scores by the total number of answered questions
Pay attention!	Item 24, 25, 26, 27, and 28 should be reverse coded by subtracting the score from 5
Generic application:	For application in different health conditions, replace the name of the health condition with the specific health condition to be assessed for stigma

For children: Self-stigma

Child Attitude Towards Illness Scale (CATIS)	
From the perspective of:	Stigmatised
Measures:	Self-stigma
Health condition:	Epilepsy, asthma, chronic physical conditions
Languages:	Available in English, possibly more
Number of questions:	13
Answer options (score):	Opposite adjectives (e.g. sad to happy, fair to unfair) in a 5-point response format as well as a frequency response scale (never to very often)
Method of administration:	Self-report
Outcome:	Mean of all items. The higher the mean score, the more positive the attitude towards having a certain health condition
Tips:	The questionnaire can be used in a self-report format among children from the age of 8, as well as with adolescents. To calculate a mean attitude sum score, the reverse coded questions should be recoded (score 1→5, 2→4, 4→2, 5→1) after which the scores on the single questions can be summed and divided by the total number of questions (13)
Pay attention!	Eight reverse coded questions namely item 1, 2, 4, 5, 7, 9, 11, 13
Generic application:	Yes, insert the specific health condition in the questions

Impact of stigma

The Participation Scale (P-scale)	
From the perspective of:	Stigmatised
Measures:	Severity of participation restrictions
Health condition:	Leprosy, HIV / AIDS, disability, generic
Languages:	Available in at least 25 languages, including Arabic, Bahasa Indonesia, Bangla, English, Hindi, Kiswahili, Nepali, Tamil, Thai, Vietnamese and Yoruba
Number of questions:	18
Answer options (score):	First level: 5 options: not specified, yes, sometimes, no, irrelevant. If yes or sometimes on the first level then second level problem assessment: 4 options: no problem (1), small problem (2), medium problem (3), large problem (5)
Method of administration:	Interview-based
Outcome:	Item sum score: A high sum score indicates a high level of participation restrictions
Tips:	A cut off point for what is 'normal' (not having significant participation restrictions) was found to be 12 in several countries. However, this may differ between areas
Pay attention!	Two-level answer options
Generic application:	Yes. No specific adaptations necessary

Perceived Stigma

Explanatory Model Interview Catalogue (EMIC) stigma scale for the community	
From the perspective of:	Stigmatisers
Measures:	Attitudes towards affected persons
Health condition:	Leprosy, HIV / AIDS, disability, generic
Languages:	Available in multiple languages, including: English, Marathi, Bengali, Nepali, Tamil, Bahasa Indonesia
Number of questions:	15
Answer options (score):	4 options: Yes (3), possibly (2), uncertain (1), no (0)
Method of administration:	Interview-based
Outcome:	Item sum score. The higher the score, the more negative the attitudes from the community member towards affected persons
Tips:	To calculate the attitude towards affected persons, the item scores should be summed up to create a total sum score
Pay attention!	-
Generic application:	Yes, insert the specific health condition in the questions

Social Distance

Social Distance Scale (SDS)	
From the perspective of:	Stigmatisers
Measures:	Social distance to a person with a particular condition (possibly described in a vignette)
Health condition:	Mental illness
Languages:	Available in: English, possibly more
Number of questions:	7
Answer options (score):	4 options: 'definitely willing' to 'definitely unwilling'
Method of administration:	Self-report
Outcome:	Item sum score. Higher mean scores indicate tendency to keep more social distance with the person affected by the health condition
Tips:	To calculate the social distance score, the item scores should be summed up to create a total sum score
Pay attention!	Questions need adaptation if the scale is used without an vignette. Also cultural adaptation is needed when using the vignette outside the USA (regarding currency)
Generic application:	Yes, insert the specific health condition in the questions and vignette

Annex 5: Instruments recommended for generic use

Internalized Stigma of Mental Illness Scale (ISMI), adjusted for leprosy affected persons						
No.		**Strongly disagree**	**Disagree**	**Agree**	**Strongly Agree**	
		1	**2**	**3**	**4**	**Score**
	Alienation					
1	I feel out of place in the world because I have leprosy					
2	Having leprosy has spoiled my life					
3	People without leprosy could not possibly understand me					
4	I am embarrassed or ashamed that I have leprosy					
5	I am disappointed in myself for having leprosy					
6	I feel inferior to others who don't have leprosy					
	Stereotype Endorsement					
7	Stereotypes about leprosy affected people apply to me					
8	People can tell that I have leprosy by the way I look					
9	Because I have leprosy, I need others to make most decisions for me					
10	People with leprosy cannot live a good, rewarding life					
11	Leprosy affected people should not marry					
12	I can't contribute anything to society because I have leprosy					
	Discrimination Experience					
13	People discriminate against me because I have leprosy					
14	Others think that I can't achieve much in life because I have leprosy					

Internalized Stigma of Mental Illness Scale (ISMI), adjusted for leprosy affected persons						
No.		**Strongly disagree**	**Disagree**	**Agree**	**Strongly Agree**	
		1	**2**	**3**	**4**	**Score**
	Discrimination Experience					
15	People ignore me or take me less seriously just because I have leprosy					
16	People often patronize me, or treat me like a child, just because I have leprosy					
17	Nobody would be interested in getting close to me because I have leprosy					
18	I don't talk about myself much because I don't want to burden others with my leprosy					
19	I don't socialize as much as I used to because my leprosy might make me look 'weird'					
20	Negative stereotypes about leprosy keep me isolated from the normal world					
21	I stay away from social situations in order to protect my family or friends from embarrassment					
22	Being around people who don't have leprosy makes me feel out of place or inadequate					
23	I avoid getting close to people who don't have leprosy to avoid rejection					
	Stigma resistance					
24*	I feel comfortable being seen in public with a person obviously affected by leprosy					
25*	In general , I am able to live life the way I want to					
26*	I can have a good fulfilling life, despite my leprosy					
27*	People with leprosy make important contributions to society					
28*	Living with leprosy has made me a tough survivor					

** Reverse: subtract from 5*

Please note:

- If you want to use this in a health condition other than leprosy, please change 'leprosy' in each question to this specific health condition.

- For calculating the overall score on this scale, please pay attention to the following. Before calculation of the sum score, items 24-28 should be recoded to get the correct results (score 1→4, 2→3, 3→4, 4→1). After this, the scores on the single items can be summed and divided by the total number of questions (28). The higher the mean score, the greater the evidence of self-stigma.

Scientific reading (please see supporting website or contact Infolep):

- Boyd Ritsher, J.E. 2003. Internalized Stigma of Mental Illness: Psychometric Properties of a New Measure. Psychiatry Research, 121, (1), 31-49

- Rensen, C. Bandyopadhyay, S. Gopal, P.K. & Van Brakel, W. 2010. Measuring leprosy-related stigma – a pilot study to validate a toolkit of instruments. Disability and Rehabilitation 2011; 33(9):711-719

Child Attitude Towards Illness Scale (CATIS)							
No.		**1**	**2**	**3**	**4**	**5**	**Score**
1	How good or bad do you feel it is that you have [condition]?	Very good	A little good	Not sure	A little bad	Very bad	*reverse
2	How fair is it that you have [condition]?	Very fair	A little fair	Not sure	A little unfair	Very unfair	*reverse
3	How happy or sad is it for you to have [condition]?	Very sad	A little sad	Not sure	A little happy	Very happy	
4	How bad or good do you feel it is to have [condition]?	Very good	A little good	Not sure	A little bad	Very bad	*reverse
5	How often do you feel that your [condition] is your fault?	Never	Not often	Some-times	Often	Very often	*reverse
6	How often do you feel that your [condition] keeps you from doing things you like to do?	Never	Not often	Some-times	Often	Very often	*reverse
7	How often do you feel that you will always be sick?	Never	Not often	Some-times	Often	Very often	
8	How often do you feel that your [condition] keeps you from starting new things?	Never	Not often	Some-times	Often	Very often	*reverse
9	How often do you feel different from others because of your [condition]?	Never	Not often	Some-times	Often	Very often	
10	How often do you feel bad because you have [condition]?	Never	Not often	Some-times	Often	Very often	*reverse
11	How often do you feel sad about being sick?	Never	Not often	Some-times	Often	Very often	
12	How often do you feel happy even though you have [condition]?	Never	Not often	Some-times	Often	Very often	*reverse
13	How often do you feel just as good as other kids your age even though you have [condition]?	Never	Not often	Some-times	Often	Very often	*reverse

Please note:

- Please change '[condition]' into the specific health condition you are investigating, such as 'leprosy'.

- For calculating the overall score on this scale, please pay attention to the

following. Before calculation of the sum score, items 1, 2, 4, 5, 7, 9, 11, and 13 should be recoded to get the correct results (score 1→5, 2→4, 4→2, 5→1). After this, the scores on the single items can be summed and divided by the total number of questions (13). The higher the mean score, the more positive the attitude towards having a certain health condition.

Scientific reading (please see supporting website or contact Infolep):

- Heimlich, T.E. Westbrook, L.E., Austin, J.K., Cramer, J.A., & Devinsky, O. 2000. Brief report: adolescents' attitudes toward epilepsy: further validation of the Child Attitude toward Illness Scale (CATIS). *Journal of paediatric psychology*, 25, (5) 339-345

- Austin, J.K. & Huberty, T.J. 1993. Development of the Child Attitude toward Illness Scale. *Journal of Paediatric Psychology*, 18 (4) 467-480

Explanatory Model Interview Catalogue (EMIC) stigma scale, adapted for leprosy affected people						
No.		**Yes**	**Possibly**	**Un-certain**	**No**	
		3	**2**	**1**	**0**	**Score**
1	If possible, would you prefer to keep people from knowing about leprosy?					
2	Have you discussed this problem with the person you consider closest to you, the one whom you usually feel you can talk to most easily?					**reverse*
3	Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?					
4	Have you ever been made to feel ashamed or embarrassed because of this problem?					
5	Do your neighbours, colleagues or others in your community have less respect for you because of this problem?					
6	Do you think that contact with you might have any bad effects on others around you even after you have been treated?					
7	Do you feel others have avoided you because of this problem?					
8	Would some people refuse to visit your home because of this condition even after you have been treated?					
9	If they knew about it would your neighbours, colleagues or others in your community think less of your family because of this problem?					
10	Do you feel that your problem might cause social problems for your children in the community?					
11A	Do you feel that this disease has caused problems in getting married? *(Unmarried only)*					
11B	Do you feel that this disease has caused problems in your marriage? *(Married only)*					

Explanatory Model Interview Catalogue (EMIC) stigma scale, adapted for leprosy affected people						
No.		**Yes**	**Possibly**	**Un-certain**	**No**	
		3	**2**	**1**	**0**	**Score**
12	Do you feel that this disease makes it difficult for someone else in your family to marry?					
13	Have you been asked to stay away from work or social groups?					
14	Have you decided on your own to stay away from work or social group?					
15	Because of leprosy people think you also have other health problems					

Please note:

- If you want to use this in a health condition other than leprosy, please change 'leprosy' in each question to this specific health condition.

- For each question, please mark this statement is true; yes (3), possibly (2), uncertain (1), or no (0)

- The scores on the single questions should be added up to get a sum score. Before calculation of the sum score, question 2 should be recoded to get the correct results. (3→0, 2→1, 1→2, 0→3) The outcome score indicates the perceived stigma. The higher the score, the higher the level of perceived stigma

Scientific reading (please see supporting website or contact Infolep – www.infolep.org):

- Weiss, M. 1997. Explanatory Model Interview Catalogue (EMIC): Framework for comparative study of illness. *Transcultural Psychiatry*, 34, (2) 235-263

Participation Scale (P-scale) v.6.0											
No.		**Not answered**	**Yes**	**Sometimes**	**No**	**Irrelevant**	**No problem**	**Small**	**Medium**	**Large**	**Score**
1	Do you have equal opportunity as your peers to find work?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
2	Do you work as hard as your peers do? (same hours, type of work etc)										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
3	Do you contribute to the household economically in a similar way to your peers?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
4	Do you make visits outside your village / neighbourhood as much as your peers do? (except for treatment) e.g. bazaars, markets										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
5	Do you take part in major festivals and rituals as your peers do? (e.g. weddings, funerals, religious festivals)										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
6	Do you take as much part in casual recreational / social activities as do your peers? (e.g. sports, chat, meetings)										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
7	Are you as socially active as your peers are? (e.g. in religious/community affairs)										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
8	Do you have the same respect in the community as your peers?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
9	Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
10	Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
11	Do you visit other people in the community as often as other people do?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	

Participation Scale												
No.		**Not answered**	**Yes**	**Sometimes**	**No**	**Irrelevant**	**No problem**	**Small**	**Medium**	**Large**	**Score**
12	Do you move around inside and outside the house and around the village / neighbourhood just as other people do?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
13	In your village / neighbourhood, do you visit public places as often as other people do? (e.g. schools, shops, offices, market and tea / coffee shops)										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
14	In your home, do you do household work?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
15	In family discussions, does your opinion count?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
16	Do you help other people (e.g. neighbours, friends or relatives)?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
17	Are you comfortable meeting new people?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
18	Do you feel confident to try to learn new things?										
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	

Comment:	**Total:**

Name: _____

Age: _____ Gender: _____

Interviewer: _____ Date of interview: ___ / ___ / _____

Grades of participation restriction

No significant restriction	0 - 12	Severe restriction	33 - 52
Mild restriction	13 - 22	Extreme restriction	53 - 90
Moderate restriction	23 - 32		

Please note:

- There is a users manual of this questionnaire available at the supporting website; www.infolep.org/stigma-guides

Scientific reading (please see supporting website or contact Infolep) :

- Van Brakel, W.H., Anderson, A.M., Mutatkar, R.K., Bakirtzief, Z., Nicholls, P.G., Raju, M.S., & Das-Pattanayak, R.K. 2006. The Participation Scale: measuring a key concept in public health. Disability and Rehabilitation, 28, (4), 193-203.

- Rensen, C. Bandyopadhyay, S. Gopal, P.K. & Van Brakel, W. 2010. Measuring leprosy-related stigma – a pilot study to validate a toolkit of instruments. Disability and Rehabilitation, 33, (9), 711-719.

Explanatory Model Interview Catalogue (EMIC) stigma scale for the community, adjusted for leprosy						
No.		**Yes**	**Possibly**	**No**	**Don't know**	
		2	**1**	**0**	**0**	**Score**
1	Would a person with leprosy keep others from knowing, if possible?					
2	If a member of your family had leprosy, would you think less of yourself, because of this person's problem?					
3	In your community, does leprosy cause shame or embarrassment?					
4	Would others think less of a person with leprosy?					
5	Would knowing that someone has leprosy have an adverse effect on others?					
6	Would other people in your community avoid a person affected by leprosy?					
7	Would others refuse to visit the home of a person affected by leprosy?					
8	Would people in your community think less of the family of a person with leprosy?					
9	Would leprosy cause problems for the family?					
10	Would a family have concern about disclosure if one of their members had leprosy?					
11	Would leprosy be a problem for a person to get married?					
12	Would leprosy cause problems in an on-going marriage?					
13	Would having leprosy cause a problem for a relative of that person to get married?					
14	Would having leprosy cause difficulty for a person to find work?					
15	Would people dislike buying food from a person affected by leprosy?					

Please note:

- If you want to use this in a health condition other than leprosy, please change 'leprosy' in each question to this specific health condition.

- For each question, please mark this statement is true; yes (2), possibly (1), no (0), or I don't know (0)

- To calculate the attitude towards affected persons – score, the item scores should be summed up to create a total sum score. The higher the score, the greater the evidence for negative attitudes from the community member towards affected persons

Scientific reading (please see supporting website or contact Infolep – www.infolep.org):

- Weiss, M. 1997. Explanatory Model Interview Catalogue (EMIC): Framework for comparative study of illness. *Transcultural Psychiatry*, 34, (2) 235

- Rensen, C. Bandyopadhyay, S. Gopal, P.K. & Van Brakel, W. 2010. Measuring leprosy-related stigma – a pilot study to validate a toolkit of instruments. Disability and Rehabilitation, 33, (9), 711-719.

Social Distance Scale (SDS)

Please read the following statement (example vignette):

Rahman is a 23-year-old man. He has been treated for leprosy during the past year. The doctor has declared him cured, even though some of the fingers on his right hand are still bent and his skin is still dark, because of the treatment. Rahman has a job in the local small business that belongs to his uncle. He earns Rp 1.2 million per month and is doing well in his job. He is a little bit slower than before, because of the effects of leprosy on his hand, but the employer never complained about that. At his job, Rahman gets along well with his colleagues. Rahman would like to get married. He is considering joining a local youth organization, so he can meet people of the same age. He also hopes to get a better job to be able to earn more than in his present job.

Social Distance Scale (SDS)						
No.		**Definitely willing**	**Probably willing**	**Probably unwilling**	**Definitely unwilling**	
		0	**1**	**2**	**3**	**Score**
1	How would you feel about renting a room in your home to someone like Rahman?					
2	How would you feel having someone like Rahman as a neighbour?					
3	How about having someone like Rahman as a caretaker of your children for a couple of hours?					
4	How about having one of your children marry someone like Rahman?					
5	How would you feel about introducing Rahman to a young woman you are friendly with?					
6	How would you feel about recommending someone like Rahman for a job working for a friend of yours?					

Please note:

- If you want to use this for a health condition other than leprosy, please change the vignette according to that health condition. Note that a new version should be validated first.

- You may need to use a vignette with a female subject for use with women.

- There is also a possibility to use this scale without a vignette; to do this, the questions should be adjusted for this. (e.g. question 1: How would you feel about renting a room in your home to a person with leprosy?)

- To calculate the social distance score, the item scores should be summed up to create a total sum score. The higher the score, the more the person has a tendency to keep social distance with the person affected by the health condition.

Scientific reading (please see supporting website or contact Infolep – www.infolep.org):

- Link, B.G. Cullen, F.T. Frank, J. Wozniak, J.F. 1987. The Social Rejection of Former Mental Patients: Understanding Why Labels Matter. *The American Journal of Sociology*, 92 (6): 1461-1500

ILEP

This Guide is part of a series of four Guides to reduce stigma. The Guides are for all managers, health and social workers and service staff who have to deal with stigma in leprosy and other health conditions. These Guides provide evidence-based and best-practice information from different disciplines, and recommendations for field workers on how to reduce stigma against and among affected persons and in the community.

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